

# Unhealthy Disabled: Treating Chronic Illnesses as Disabilities

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*Chronic illness is a major cause of disability, especially in women. Therefore, any adequate feminist understanding of disability must encompass chronic illnesses. I argue that there are important differences between healthy disabled and unhealthy disabled people that are likely to affect such issues as treatment of impairment in disability and feminist politics, accommodation of disability in activism and employment, identification of persons as disabled, disability pride, and prevention and “cure” of disabilities.*

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The relationship between disability and illness is a problematic one. Many people are disabled by chronic and/or life-threatening illnesses, and many people with disabilities not caused by illness have chronic health problems as consequences of their disabilities; but modern movements for the rights of people with disabilities have fought the identification of disability with illness, and for good reasons. This identification contributes to the medicalization of disability, in which disability is regarded as an individual misfortune, and people with disabilities are assumed to suffer primarily from physical and/or mental abnormalities that medicine can and should treat, cure, or at least prevent (Oliver 1990; Morris 1991). Moreover, Ron Amundson argues that, since illness is perceived as “globally incapacitating,” identifying disability with illness fosters the myth that people with disabilities are globally incapacitated, which in turn contributes to the social devaluation of disabled people (Amundson 1992, 113–14). Perhaps most importantly, in the recent past, many healthy people with disabilities were forced to live in long-term care institutions under medical supervision simply because they needed services to perform tasks of daily living. In those institutions, medical personnel controlled every aspect

of their lives, and little or no provision was made for them to work, to receive education, or to participate in life outside the institutions. At least in Canada, not everyone who could live outside an institution has achieved that goal, and institutionalization (especially when support networks break down) remains a threat to some people with disabilities who have achieved independent living (for example, see Snow 1992). All these reasons motivate disabled activists and other people with disabilities to distinguish themselves from those who are ill.

For example, in her recent book *Exile and Pride: Disability, Queerness and Liberation* (1999), Eli Clare describes her resistance to the medical model of disability in terms that emphasize her distance from sick people:

To frame disability in terms of a cure is to accept the medical model of disability, to think of disabled people as sick, diseased, ill people. . . . My CP simply is not a *medical* condition. I need no specific medical care, medication, or treatment for my CP; the adaptive equipment I use can be found in a computer catalog, not a hospital. Of course, disability comes in many varieties. Some disabled people, depending on their disabilities, may indeed have pressing medical needs for a specific period of time or on an ongoing basis. But having particular medical needs differs from labeling a person with multiple sclerosis as sick, or thinking of quadriplegia as a disease. The disability rights movement, like other social change movements, names systems of oppression as the problem, not individual bodies. In short it is ableism that needs the cure, not our bodies. (Clare 1999, 105–6)

Although she acknowledges that some people with disabilities have medical needs, including someone with multiple sclerosis (MS, which qualifies as a chronic illness), Clare criticizes the medical model for thinking of disabled people as “sick, diseased, ill people” and says that their bodies do not need cure. Yet some people with disabilities *are* sick, diseased, and ill. Social constructionist analyses of disability, in which oppressive institutions and policies, prejudiced attitudes, discrimination, cultural misrepresentation, and other social injustices are seen as the primary causes of disability, can reduce attention to those disabled people whose bodies are highly medicalized because of their suffering, their deteriorating health, or the threat of death. Moreover, some unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amount of social justice can eliminate. Therefore, some very much want to have their bodies cured, not as a substitute for curing ableism, but in addition to it. There is a danger that acknowledging these facts might provide support for those who prefer the individualized, medicalized picture of disability. Thus, in promoting the liberatory vision of

social constructionism, it is safer and more comfortable for disability activism to focus on people who are healthy disabled.

Despite the problematic relationship between disability and illness, many people who are disabled by chronic illnesses are involved in disability politics and contribute to social constructionist analyses, and disability groups have increasingly welcomed into their activities people with HIV/AIDS, fibromyalgia, myalgic encephalomyelitis/ chronic fatigue immune dysfunction syndrome (ME/CFIDS), and other chronic illnesses. However, there are important differences between healthy disabled and unhealthy disabled people that are likely to affect such issues as treatment of impairment in disability politics and feminism, accommodation of disability in activism and employment, identification of persons as disabled, disability pride, and prevention and so-called “cure” of disabilities. Here I hope to introduce and perhaps clarify some of those differences, and to open a conversation about the relationships between illness and disability and between unhealthy and healthy people with disabilities.

The issues I will be raising are particularly important to women because women are more likely than men to be disabled by chronic illnesses (Morris 1994; Trypuc 1994), and women (including women with other disabilities) suffer more ill health than men (Carroll and Niven 1993). Women live longer than men, but much of that extra living is done with a disabling chronic illness (Carroll and Niven 1993; *Report on the Health of Canadians* 1996). Accommodating chronic illnesses in disability politics and feminism is essential to many disabled women’s participation in them. Thus, as we shall see, it is women with disabilities who have been most outspoken about some of these issues.

#### WHO IS WHO?

When I speak of people who are “healthy disabled,” I mean people whose physical conditions and functional limitations are relatively stable and predictable for the foreseeable future. They may be people who were born with disabilities or people who were disabled by accidents or illnesses later in life, but they regard themselves as healthy, not sick, they do not expect to die any sooner than any other healthy person their age, and they do not need or seek much more medical attention than other healthy people (I will not try to give a definition of health, which is too big a topic to discuss here, but I am assuming that healthy people’s functional limitations and bodily suffering are fairly stable and do not motivate them to seek medical treatment or cures).

Notice that “healthy disabled” is a category with fluctuating and sometimes uncertain membership. Many people who seem to have stable disabilities now will encounter illness and changing disability later in life (for example, post-polio syndrome has destabilized the health and abilities of some people who had recovered from polio, with residual disability, decades ago), and some people

who seem to have stable disabilities also have chronic or recurrent health problems, either as consequences of their disabilities or independently of them. Thus, many of the problems I describe here as problems of unhealthy disabled people have been or will be problems of people who are now healthy disabled.

Defining what I mean by chronic illness would help to clarify the distinction between healthy and unhealthy people with disabilities, but it is not easy to pin down chronic illnesses with a definition.<sup>1</sup> Usually, they are understood to be illnesses that do not go away by themselves within six months, that cannot reliably be cured, and that will not kill the patient any time soon. I think that any practical concept of chronic illness has to be patient-centered or illness-centered, rather than based on diagnosis or disease classification, because many diseases cannot reliably be categorized into chronic and non-chronic. Nevertheless, a brief discussion of the variety of ways that diseases can cause chronic illness may be helpful.

Some diseases, such as lupus or diabetes, are known to be *typically* chronic. Physicians do not expect to cure them, and, once diagnosed, patients more or less expect to have to live with them (depending on how informed they are and how inclined they are to believe in miraculous cures or rapid progress in scientific medicine). A few patients with these diseases do recover their health instead of remaining chronically ill, but most do not. On the other hand, patients do not expect to die soon from these diseases. Nevertheless, many of the recognized chronic diseases, such as lupus, sometimes occur in acute forms that kill the patient quickly, and many of them, such as diabetes, are expected to kill the patient eventually, either by wearing down the patient's health or by creating severe, life-threatening episodes of illness.

Other diseases, such as infectious mononucleosis or Lyme disease, are usually acute but can last for years in some patients, making them chronically ill by any patient-centered definition. People who are chronically ill with these diseases are likely to have trouble getting recognition of their illnesses—if not by the medical profession, then by friends, relatives, acquaintances, employers, insurers, and others who believe that they should have recovered from their diseases long ago. Still other diseases are acute or chronic, depending on the treatment available to patients. HIV infection most often becomes the acute and deadly disease AIDS in poor countries, but in wealthy countries, where expensive treatment can slow its progress, it can frequently be a chronic disease.

Some diseases, such as MS and rheumatoid arthritis, can behave like recurring acute illnesses, with periods of extreme debility and periods of normal (or nearly normal) health, or they can have virtually constant symptoms (such as fatigue or pain) and/or be characterized by recurring acute episodes that leave behind permanent losses of function (such as paralysis caused by MS). Mental

illnesses are sometimes acute, sometime recurring, and sometimes chronically debilitating. For example, schizophrenia and depression go in and out of remission for many people. Whether the mental illnesses are diseases is still controversial (see Agich 1997, 229–37), but clearly any adequate concept of illness includes them because of the involuntary suffering and loss of function they cause. I consider illnesses that go into remission chronic when they require prolonged medical treatment or surveillance, or when patients must fear recurrences because there is no reasonable expectation of cure.

The questions “Is my illness temporary?” and “How long will it last?” are often unanswered or answered uncertainly by medicine. This creates difficulties of identity both for the person who is ill (am I disabled or just sick for a while?) and for other people. Christine Overall describes an experience of being ill for more than a year with a painful, debilitating condition initially diagnosed as rheumatoid arthritis and then re-diagnosed as viral arthritis. She says that during the time she was ill, she identified with people with disabilities, was constructed as a person with disabilities, and inhabited the world of people with disabilities. However, she also experienced a strong pressure to “pass for normal” (Overall 1998, 155). People minimized her illness, ignored it, denied it, and urged her to get over it. Overall attributes some of this reaction to ageism, speculating that disability is “easier to recognize and tolerate . . . in older people than in younger ones” (1998, 162).

My own analysis is that young and middle-aged people with chronic illnesses inhabit a category not easily understood or accepted. We are considered too young to be ill for the rest of our lives, yet we are not expecting cure or recovery.<sup>2</sup> We cannot be granted the time-out that is normally granted to the acutely ill (or we were given it at first and have now used it up, overused it), yet we seem to refuse to return to pre-illness life. We are not old enough to have finished making our contributions of productivity and/or caregiving; old people with chronic illnesses may be seen to be entitled to rest until they die. And we are not expected to die any time soon, so we are going to hang around being sick for a long while. Cheri Register calls us “the interminably ill” (Register 1987, ix).

Moreover, those of us with chronic illnesses do not fit most people’s picture of disability. The paradigmatic person with a disability is healthy disabled and permanently and predictably impaired. Both attitudes toward people with disabilities and programs designed to remove obstacles to their full participation are based on that paradigm. Many of us with chronic illnesses are not obviously disabled; to be recognized as disabled, we have to remind people frequently of our needs and limitations. That in itself can be a source of alienation from other people with disabilities, because it requires repeatedly calling attention to our impairments.

## IMPAIRMENT

Many of the issues I raise in this article would be classified as issues of *impairment* in the literature of disability activism and disability studies. Disability activists and scholars usually distinguish impairment from disability, treating impairment as the medically defined condition of a person's body/mind, and disability as the socially constructed disadvantage based upon impairment. This distinction follows the United Nations' definition of impairment as "any loss or abnormality of psychological, physiological, or anatomical structure or function" (U.N. 1983, I.c., 6–7). The U.N.'s attempt to give an objective, universal definition of impairment, which I have criticized elsewhere (Wendell 1996), connects impairment to the medical institutions that measure structure and function and set the standards of "normality." I believe this connection has contributed to neglect of the realities of impairment in disability activism and disability studies, because it makes attention to impairment seem irrelevant to or in conflict with the social constructionist analyses of disability they employ.

Illness is equated with impairment, even by disability activists and scholars, in ways that disability is not; hence there is anxiety to assure nondisabled people that disability is not illness. Another consequence is the pressure to be (or to pass as) healthy disabled both within disability activism and outside it. Because disability activists have worked hard to resist medicalization and promote the social model of disability, activists sometimes feel pressured to downplay the realities of fluctuating impairment or ill health. Cheryl Marie Wade (1994, 35) has criticized the new image of "the able-disabled" and the reluctance among disability activists to admit to weakness and vulnerability. She found that her identity as an activist made it difficult to acknowledge her physical limitations until her body broke down, endangering both her health and her self-esteem. Outside disability activism, there is pressure to conform to an inspiring version of the paradigm of disability. Those people with disabilities who can best approximate the activities and appearance of nondisabled people (that is, those who can make others forget they are disabled) will be allowed to participate most fully in the activities of their society.

British feminist disability activist Liz Crow has written a powerful critique of "our silence about impairment" within disability movements. She says:

Our insistence that disadvantage and exclusion are the result of discrimination and prejudice, and our criticisms of the medical model of disability, have made us wary of acknowledging our experiences of impairment. Impairment is safer not mentioned at all.

This silence prevents us from dealing effectively with the difficult aspects of impairment. Many of us remain frustrated and disheartened by pain, fatigue, depression and chronic illness, including the way they prevent us from realizing our potential or railing fully against disability (our experience of exclusion and discrimination); many of us fear for our futures with progressive or additional impairments; we mourn past activities that are no longer possible for us; we are afraid we may die early or that suicide may seem our only option; we desperately seek some effective medical intervention; we feel ambivalent about the possibilities of our children having impairments; and we are motivated to work for the prevention of impairments. Yet our silence about impairment has made many of these things taboo and created a whole new series of constraints on our self-expression. (Crow 1996, 209–10)

Crow emphasizes the need to focus on both disability *and* impairment, and she acknowledges that “impairment *in itself* can be a negative, painful experience” (Crow 1996, 219). She urges people with disabilities to adopt a new approach to impairment that includes not only the medically-based descriptions of our bodies/minds but also our experiences of our bodies/minds over time and in variable circumstances, the effects they have on our activities, the feelings they produce, and any concerns about them that impaired individuals might have.

It seems possible to pay more attention to impairment while supporting a social constructionist analysis of disability, especially if we focus our attention on the phenomenology of impairment, rather than accepting a medical approach to it. Knowing more about how people experience, live with, and think about their own impairments could contribute to an appreciation of disability as a valuable difference from the medical norms of body and mind. Moreover, recognition of impairment is crucial to the inclusion of people with chronic illnesses in disability politics. Chronic illness frequently involves pain, fatigue, dizziness, nausea, weakness, depression, and/or other impairments that are hard to ignore. Everything one does, including politics, must be done within the limitations they present. The need to accommodate them is just as great, if more problematic (see below), as the need to accommodate blindness or hemiplegia, but they cannot be accommodated if they are not acknowledged and discussed openly.

Liz Crow points out that ignoring impairment can reduce the relevance of the social model of disability to certain groups, such as women, among whom (in England) arthritis is the most common cause of impairment, manifested

in pain (1996, 221). I would add that pain and/or fatigue are major sources of impairment in many chronic illnesses that are more common in women than in men, including rheumatoid arthritis, fibromyalgia, lupus, ME/CFIDS, migraine headache, MS, and depression. This is not to say that men do not suffer from impairments of chronic illness, but that attempting to ignore impairment in disability politics may alienate or marginalize more women than men. Jenny Morris reports that restoring the experience of impairment to disability politics was regarded as a women's issue in the series of meetings of disabled women that led to the book, *Encounters with Strangers: Feminism and Disability*, in which Crow's critique of the social model was published (Morris 1996, 13).

When feminist politics ignores their experience of impairment, there are different but equally disturbing sources of disabled women's alienation from feminism or their marginalization within it. Feminist organizations have become more aware of the need to make their activities accessible to women who use wheelchairs, women who need written material in alternative formats, and women who need Sign Language translation, but much feminist practice still assumes a consistently energetic, high-functioning body and mind, and certainly not a body and mind that are impaired by illness. (I will discuss accommodating chronic illnesses in political practice in the next section.) Moreover, in their writing and organizing, most feminists still assume that feminists are giving, and not receiving, care, and that all significant contributions to feminist movements happen in meetings, at public events, and in demonstrations on the streets. The accepted image of a good feminist still includes handling paid work and family responsibilities and having plenty of energy left over for political activity in the evenings or on weekends. In these circumstances, women with chronic illnesses are likely to find it difficult to participate in feminist movements or to identify themselves as feminists.

Not only unhealthy people with disabilities but many healthy disabled people would benefit from more recognition of impairment in both disability and feminist politics. Some disabilities that are not illnesses and do not cause illnesses do involve impairments similar to those caused by chronic illnesses. It has been difficult, for example, for people with some brain injuries to have their impairments understood and accommodated, because they are more like impairments of chronic illnesses—transitory and unpredictable—than those of paradigmatic, stable disabilities. They may include both fatigue and intermittent cognitive impairments that are exacerbated by fatigue, such as difficulty concentrating and recalling words.

Fatigue is one of the most common and misunderstood impairments of chronic illness. The fatigue of illness is different in three critical respects from the ordinary fatigue experienced by healthy people: it is more debilitating, it lasts longer, and it is less predictable. Every activity, including thinking, watching, listening, speaking, and eating, requires energy. It is possible to be

too fatigued to do any of these. Anyone who has had severe influenza may recall being too fatigued to have a conversation, to follow a simple story, or to make a decision. That experience of fatigue is closer to the fatigue of MS, rheumatoid arthritis, fibromyalgia, depression, or ME/CFIDS than the fatigue of a healthy person at the end of a hard day. A good night's sleep rarely cures the profound fatigue of illness; it may last for days or weeks with no apparent improvement, or it may fluctuate, allowing some activity punctuated by periods of total exhaustion. And unlike the fatigue of influenza, which will gradually improve as one's body recovers from infection, the fatigue of chronic illness is unpredictable. It may appear first thing in the morning on the tenth day of a restful vacation or in the middle of an energetic day's work. Reasonable precautions may help to prevent it, but it resists control.

Fatigue may be a primary symptom of a chronic illness, or it may be caused by other symptoms, such as pain, anorexia, or depressed mood. Thus, fluctuating and severely limited energy is a common impairment of people with chronic illnesses. Of course, not everyone with a chronic illness experiences this impairment, but it is an important example, not only because many of us have impaired energy, but because it is one of the most challenging impairments to accommodate.

#### ACCOMMODATING CHRONIC ILLNESSES

Fluctuating abilities and limitations can make people with chronic illnesses seem like unreliable activists, given the ways that political activity in both disability and feminist movements are structured. On a bad day of physical or mental illness, we may be unable to attend a meeting or workshop, to write a letter, to answer the phone, or to respond to e-mail. We may need notice in advance of work to be done, in order to work only on good days or more slowly on days when we are very ill. We may need to work in teams, so that someone else can take over when we cannot work at all. We may need to send a written speech to a meeting to be read by someone else because we are too sick to attend and read it in person. We need others to understand that our not showing up does not mean that we are not committed to the group, event, or cause.

Commitment to a cause is usually equated to energy expended, even to pushing one's body and mind excessively, if not cruelly. But pushing our bodies and minds excessively means something different to people with chronic illnesses: it means danger, risk of relapse, hospitalization, long-lasting or permanent damage to our capacities to function (as for some people with MS). And sometimes it is simply impossible; people get too tired to sit up, to think, to speak, to listen, and there are no reserves of energy to call upon. Yet in political activity, all-day meetings and evening events after a full day's work are assumed to be appropriate. Stamina is required for commitment to a cause.

I feel uneasy describing these conflicts between the demands of activism and the realities of chronic illness, because I do not want to supply good reasons for regarding those of us who are perpetually ill as social burdens rather than social contributors. This is probably the same uneasiness that healthy disabled people feel about focusing attention on their impairments. I can only hope, as Liz Crow does (Crow 1996, 222–25), that probing these threatening topics will lead eventually to facing and solving some problems. If there is to be more than token participation by unhealthy disabled people over the long term, there will have to be changes in the structure, culture, and traditions of political activism. People will have to think differently about energy and commitment, pace and cooperation.

Implementing the accommodations of pace and scheduling needed by people with chronic illnesses may inconvenience a lot of other people in a group (although, given the general silence about limitations of energy, perhaps many more people will be relieved). Moreover, everyone knows that the people who commit the most time and energy to a group will usually acquire the most power to influence the group's activities. In order for people with impaired energy to participate as equals, the relationships between time, energy, and power will have to be discussed openly and negotiated.

None of this will be easy. Conflicts and suspicions are inevitable. Management of energy is an issue, and at times a challenge, for every adult, whether nondisabled, healthy disabled, or unhealthy disabled. And it is sometimes hard to tell the difference between someone's mismanaging her/his own energy and other people's failure to accommodate her/his impaired energy. Even those of us who have lived a long time with chronic fatigue cannot always tell whether we are not trying hard enough or experiencing a physical/mental limitation, whether we need inspiration, self-discipline, or a nap. In political activism, where external pressures such as publication deadlines or responding to governmental announcements can virtually dictate the pace of the group, someone's claim to need rest may seem like shirking responsibility, especially to people who resent contributing more time or energy than others. Thus, pace and flexibility about time are bound to be controversial in any group that tries to negotiate them. Yet the only alternative is to take them for granted and make it difficult or impossible for people with impaired energy to participate.

Pace and flexibility about time are also issues of employment access for people with chronic illnesses, and here too conflict may arise—in this case, between the goals of healthy disabled people and the needs of unhealthy disabled people. We have learned that, even with strong legislation such as the Americans with Disabilities Act, it is hard to achieve accommodation of permanent, predictable disabilities in workplaces. Many employers (and nondisabled workers) resist the most straightforward requirements of wheelchair accessibility or Deaf translation. Understandably, disability activists want to

stress the message “Remove the barriers that have been erected arbitrarily against our participation, and we will perform as well as anyone else.” Insisting on accommodations of pace and time threaten this message, because working according to the employer’s schedule and at the pace he/she requires are usually considered to be aspects of job performance, even in jobs where they are not critical to the adequate completion of tasks.

Iris Marion Young has pointed out that, from the perspective of most employers, “the norm of the ‘hale and hearty’ worker” makes a necessary contribution to workplace discipline. “The ‘normal’ worker is supposed to be energetic, have high concentration abilities, be alert to adapt to changing conditions, and be able to withstand physical, mental or interactive stress in good humor. Workers who fail to measure up to one or more of these standards are ‘normally’ considered lazy, slackers, uncooperative or otherwise inadequate. All workers must worry about *failing* in the eyes of their employers . . .” (Young 2000, 172). Because many workers fail, either temporarily or permanently, to live up to this “norm,” requiring accommodation of a wide range of disabilities would call the “norm” into question and challenge employers’ power to set the standards of workplace performance. Employers would prefer to define disability narrowly and regard the vast majority of workers who do not meet their standards as unsuitable for their jobs.

Moreover, if people with chronic illnesses demand accommodations of pace and time, they may encounter resistance from other workers because of the “politics of resentment,” described here by Young:

Most workers feel put-upon and frustrated by their working conditions and the demands of their employers on their time and energy. They have to stand up all day, or have few bathroom breaks, or work overtime or at night, and their employer refuses to accommodate to their aching backs, their family pressures, their sleeplessness or difficulty in concentrating. Many workers, that is, find the demands placed on them next to overwhelming at times, and they feel barely able to cope. Rarely do they get a sympathetic ear to voice their frustrations, however, and the only agents they are allowed to blame for their difficulties are themselves. It is little wonder that they may resent people that the law requires employers to accommodate in order to enable them better to fit the work situation.

. . . Disability is a matter of degree, and it is arbitrary where the line is drawn between not disabled enough to warrant accommodation, and disabled enough. A politics of resentment motivates some people to draw that line as far down the extreme end of the continuum as possible so that almost everyone will be

legally expected to conform to the *normal* workplace demands.  
(Young 2000, 171)

On the basis of Young's analysis, I think we should expect strong resistance from both employers and workers to accommodating chronic illnesses in the workplace. This resistance may strain the resources and the solidarity of disability rights movements. Yet access to work for unhealthy disabled people will require taking what Young calls "the next step toward equal opportunity for people with disabilities," that is, challenging the prerogative of employers to define the content, qualifications, and performance criteria of work (Young 2000, 173). There are some reasons for optimism: we have a lot of potential allies to whom pace and flexibility about time make the difference between working and not working, including many nondisabled women caring for children and disabled older family members; and, as Young points out, there are many other workers, who do not identify themselves as disabled, who would benefit from "more humane and individualized workplace accommodation" (2000, 173).

#### WHO BELONGS?

Controversy about the appropriateness of accommodations of pace and time often leads to doubts about the legitimacy of the disability for which accommodation is requested. Suspicion surrounds people with chronic illnesses—suspicion about how ill/disabled we really are, how or why we became ill, whether we are doing everything possible to get well, and how mismanaging our lives, minds, or souls may be contributing to our continuing illness (Wendell 1996). Suspicion comes from medical professionals, friends, relatives, co-workers, and, understandably, from other people with disabilities.

In her study of a group of people with disabilities in Britain, Jill C. Humphrey found that there was a conspicuous silence about impairment and an associated suspicion as to whether some people belonged in the group—in other words, whether they were really disabled. In her interviews with them, group members raised this suspicion about people whose impairments were not readily apparent. Humphrey comments: "the propensity to treat only tangible impairments as evidence of a *bona fide* disability identity clearly marginalizes those with non-apparent impairments . . . whilst the reluctance or refusal to differentiate between impairments by identifying them bolsters up the claim by people with apparent impairments that they represent all disabled people" (Humphrey 2000, 67). Of course, suspicions about whether people with non-apparent impairments are really disabled are common, being the flip side of the ability to pass as nondisabled.

The ability to pass is a frequent, though not a universal, difference between unhealthy and healthy people with disabilities. Its advantages include avoiding the prejudices and daily acts of discrimination and patronizing behavior that people with obvious disabilities are subjected to at school, at work, and in other public places. Passing is sometimes voluntary, but it can also be involuntary, in that some of us will be perceived as nondisabled unless we draw attention to our disability, and sometimes even after we draw attention to it. The ability to pass makes a person *not* the paradigmatic person with a disability. Whether it makes her/him more or less acceptable to nondisabled people is unclear; someone who can pass but chooses not to may be seen as soliciting sympathy and special treatment. In either case, our ability to pass means that having our disabilities recognized as genuine is a major issue for many unhealthy disabled people. So much depends on that recognition—accommodation of our impairments, inclusion in disability politics, and, of course, our moral reputations. Because of what Young calls “the politics of resentment” (Young 2000, 171), people wonder whether someone whose disability is not obvious is faking or exaggerating it; the trustworthiness of people who claim to be disabled but do not look disabled is always in question.

Even when our disabilities are considered genuine, there is often suspicion about our role in causing them. Blame and responsibility for our disabilities are more persistent issues for unhealthy than for healthy people with disabilities. Although people disabled by accidents that they themselves caused (for example, by driving drunk) or risked unreasonably (by not wearing a helmet on a motorcycle, for example) may be blamed at first for their disabilities, that blame does not usually follow them for long, perhaps because their disabilities are relatively stable, and thus holding them responsible seems more and more pointless as time goes on. In contrast, people with chronic illnesses are likely to be blamed or held responsible not only during the process of seeking a diagnosis, but also during every relapse or deterioration of their condition, which they are expected (by doctors, loved ones, employers, and the general public) to control (Register 1987; Charmaz 1991). Fluctuations in our illnesses and abilities—which *can* be affected by our emotions, changes in our lives, and stress, but which may occur independently of them—contribute to the perception that we are responsible for our disabilities. In addition, an abundance of popular theories claim or imply that anyone can control her/his health with the right diet, exercise, attitudes, relationships, or religious beliefs; it follows from most of them that those who are unhealthy are doing something wrong, and that, if they have been told how to take better care of themselves, they are acting irresponsibly (See Wendell 1999).

## PRIDE, PREVENTION, AND "CURE"

Health is regarded as a virtue or a blessing, depending on how well a person or group of people understands that it cannot be controlled, but it is almost always regarded as a good. Among people who have the political savvy not to give thanks publicly for being nondisabled, giving thanks for being healthy is acceptable, even commendable. Healthy people with disabilities express gratitude for being healthy, people with progressive chronic illnesses express gratitude for not having gotten sicker than they have, and people with recurring or fluctuating chronic illnesses express gratitude for coming out of a relapse (as I know I do).

Of course, many people, especially nondisabled people who have little knowledge of the lives of people with disabilities, fear other kinds of disability as much as, or more than, illness, and regard physical and mental "normality" as blessings, if not virtues. Because fear of disability contributes to the social stigma of being disabled, it is one of the goals of disability politics to replace fear with the understanding that disability can be a valuable difference and that people with disabilities can be proud of their differences from nondisabled people. The question is, does this goal make sense in relation to disabling chronic illnesses? At first glance, it seems to, because chronic illness is a kind of disability, but compare "Thank God I'm not disabled" with "Thank God I'm healthy," and you see the difficulty of applying disability pride to a chronic illness.

Is illness *by definition* an evil, or have we made less progress in recognizing chronic illnesses as potentially valuable differences than we have in relation to other disabilities? (There is a third possibility: Perhaps acute illness is by definition an evil, chronic illness is not, and people confuse them. Yet if that were the case, the news that you are not going to recover from an illness and will have to live with it would be good news; but, unless you were expecting death, it is not good news. Illness, chronic or acute, is widely regarded as an evil.) Certainly it is difficult to say that one is glad to have been ill and be believed, despite the fact that many people who are or have been ill testify that it has changed them for the better. Of everything I said in my book about disability, *The Rejected Body* (1996), readers have most often questioned or been shocked by my statements that, although I would joyfully accept a cure if it were offered me, I do not need a cure and I do not regret having become ill (Wendell 1996, 83–84, 175). I suppose many people suspect I am making the best of a miserable fate, but then they probably think something very similar about other expressions of disability pride.

I do not think that those of us who appreciate having become ill are making a mistake or deceiving ourselves. Illness is not by definition an evil, but people fear and try to avoid illness because of the suffering it causes. Some of that

suffering is social and could be eliminated by social justice for people with disabilities, but some of it is not. Solidarity between people with chronic illnesses and people with other disabilities depends on acknowledging the existence of the suffering that justice cannot eliminate (and therefore on our willingness to talk about impairment). It also depends on acknowledging that illness is not *only* suffering. Like living with cerebral palsy or blindness, living with pain, fatigue, nausea, unpredictable abilities, and/or the imminent threat of death creates different *ways of being* that give valuable perspectives on life and the world. Thus, although most of us want to avoid suffering if possible, suffering is part of some valuable ways of being. If we could live the ways of being without the suffering, some of us would choose to live them. Some of us would choose to live them even if they were inseparable from the suffering. And some of us are glad to have been forced to live them, would choose to be rid of the suffering even if it meant losing the ways of being, but would hope to hold on to what we have learned from them. There are, I think, many versions of disability pride.

Disability pride has come into conflict with medical efforts to prevent disability, especially by selective abortion of potentially disabled fetuses, and with medical efforts to “cure” certain disabilities, especially deafness in children. Moreover, disability movements have criticized spending enormous amounts of public and donated money searching for “cures” while neglecting to provide the most basic services and opportunities that would improve the lives of people with disabilities. Prevention and cure both focus public attention on the medical model, which can lead us to ignore the social conditions that are causing or increasing disability among people who have impairments. Moreover, given the history of eugenics, there is reason to be skeptical about whether prevention and cure are intended primarily to prevent suffering or to eliminate “abnormalities” and “abnormal” people.

However, it is striking that everyone, including disability scholars and activists, tends to assume that prevention is desirable when the cause of disability is war, famine, poor medical care, accident, or illness, and that cure is desirable when the cause is illness. Perhaps, in these instances, it seems heartless to insist on preserving difference instead of preventing or ending suffering. Whatever our reasons, we sometimes insist on people’s rights to have impairments and sometimes assume that they would not want them, depending on the causes and circumstances of disability. I think that when we explore these different responses further, we will discover different beliefs about how much suffering is an acceptable price to pay for a difference we value, and even different beliefs about the value of suffering itself. The perspectives of people with chronic illnesses will be essential to such an exploration, because it may be as difficult for healthy disabled people to see the value of illness as for nondisabled people to see the value of disability. Only some people know what is at stake when we

contemplate preventing and curing illnesses: not only the relief of suffering, but also, as with other disabilities, ways of being human.

## NOTES

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1. In this article, I am using “sickness” and “illness” synonymously to mean suffering, limitation, and/or loss of function experienced by a person and attributed by her/him (or others) to a loss of health and not to a physical or mental condition present from birth or acquired by an injury to a specific part of the body. I am using “disease” to refer to some medically recognized diagnostic categories of physical or mental “abnormality.” Not all sicknesses and illnesses are diseases recognized by medicine, and not all medically recognized diseases cause a person to feel sick or ill. My definitions are based on ordinary use of the words; unfortunately, ordinary use does not make precise distinctions, so there are afflictions that do not fit the definitions neatly (such as chronic inflammation of an injured limb). There is a considerable philosophical literature debating the definitions of “disease,” “sickness,” “illness,” and related concepts. For a recent overview and samples of those debates, see Humber and Almeder (1997).

2. I have lived with ME/CFIDS since 1985. During the first two years of illness, I was severely impaired by fatigue, muscle pain, muscle weakness, dizziness, nausea, headaches, depression, and problems with short-term memory (especially verbal recall). All these impairments are still with me, but now they are intermittent and less severe than they were. I am able to work three-quarter-time as a professor by living a quiet, careful life. An account of my personal experience of being disabled by chronic illness can be found in *The Rejected Body: Feminist Philosophical Reflections on Disability* (1996).

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